



WASHINGTON

State Independent Living Council

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Meeting Minutes April 24, 2009 West Central Community Center Spokane, WA

Chair Romel Mackelprang called the State Independent Living Council (SILC) meeting to order at 8:53 am.

All Council Members and visitors then introduced themselves.

Members present: Romel Mackelprang, Al Neely, Linda McClain, Trina Forest, Lynnae Ruttledge, Devin Beach, Debbie Cook, Diane Hansen, Gilbert Garza, Jana Finkbonner

SILC Staff present: Rob Honan, Executive Director and Barbara Hathaway, Executive Assistant

Members Absent: Council Member: Sandra Carr and Robert Roberts (WSRC representative to the SILC).

Visitors: Von Elison, Executive Director for CWDR, Ellensburg; Jim Baker, Executive Director for DARSW, Vancouver; Charley Lane, Executive Director for dRC, Everett; Lucille Walls, Executive Director for The Alliance of People with Disabilities, Seattle; Jeff Tomlinson, Vice-chair of the CORD in Spokane, Ethan Smith, student at Eastern Washington University in Cheney; Mariah Barela, staff at CORD; Anthony Conald, staff at CORD; Hazel Colgrove from CORD; Shelley Williams from CORD; Andres Aguirre from DVR in Lacey, Karen Rosenthal from Olympia; and Dan Teachman, Board member at CORD; Lois King, CORD; Dwight McClain, volunteer at CORD; Amy Ellis of Eastern Washington Center for the Deaf and Hard of Hearing

There was a brief review of the prior day's Public Forum provided by Chair Mackelprang.

Lynnae Ruttledge announced that she received word that the state of Washington will receive \$1.8M in Title VII Part C ARRA (American Recovery and Reinvestment Act) funds. This information was emailed to her that morning, but there were no additional details provided, such

as amount per CIL. As part of this discussion, Ruttledge outlined the difference between Title VII Parts B and C as and stressed that she was talking about the ARRA (or stimulus funds) amounts rather than the yearly Title VII Parts B and C amounts.

There was a motion to approve the minutes from the January 28th and 29th meeting by Linda McClain. Devin Beach seconded the motion. The minutes were approved unanimously.

Mackelprang provided the **Chair's report**. He gave a review of a meeting held in January with the Governor's office. There were several topics discussed during that meeting, including the potential of the SILC as future a non-profit entity and restrictions on out of state travel. Ruttledge stated that the out of state travel ban is still in effect, but if out of state trips can be shown to be "judicious and defensible" then out of state travel is more likely (not definitely) to occur.

A discussion on out of state travel ensued at this point, and Debbie Cook made the comment that many groups are going to electronic meetings (phone, webcast, etc.) to cut down on out of state travel, but she realizes that the in-person conferences are far more valuable. Diane Hansen asked whether it was possible to split the state and federal dollars, but Ruttledge stated that this is not possible since the SILC needs the state funding (20%) to buy the federal monies (80%).

Speaker # 1

Von Elision, director of the Central Washington Disability Rights in Ellensburg, was the first speaker. She spoke on two issues. The first issue was an upcoming Rehabilitation Services Administration (RSA) review of her Center, which will take place June 22-24th. She stated that RSA essentially examines some consumer files; interviews several participants, board members and community members; and looks at other components of their operation which ultimately might lead to some feedback or even a corrective action plan.

Elision spent most of her time on the potential closure of Yakima Valley School (Habilitation Center). She first provided a timeline of this situation. Governor Gregoire suggested that the Habilitation Center be closed in her proposed budget (fall 2008), and that residents be transferred to other Habilitation Centers scattered throughout the state. The SILC and other disability groups agreed that the facility should be closed, but as Von said it is just more than just a financial issue - it is really a quality of life issue because individuals should choose where they wish to live. Elision stated that most individuals would prefer to live in the community with supports (attendant care, housing, transportation, case management, etc.). Shortly after the January 2009 SILC meeting, the SILC along with other statewide disability groups signed on to a letter authored by Mark Stroh of Disability Rights Washington to the legislative leadership supporting the Governor's position on this issue, but stressed the quality of life and choice perspective.

Continuing her presentation on the potential closure of Yakima Valley School, Elision outlined why some folks are opposed to the closure of the "school" (Von stressed that it is NOT a school, despite its name). For some people, it is an economic issue. Yakima Valley

School is an employer. For others (especially older parents) there is a fear factor in terms of where their adult children will live. Further, there is a very large organized lobby (mainly employees) that want to keep the “school” open. This has been a challenge for those that wish to close the facility.

To put Alison’s presentation in perspective, Ruttledge was curious about how the CILs are doing relative to moving people out of institutions. The 2007-2010 State Plan for Independent Living calls for the CILs to move at least 45 individuals out of institutions back into the community. Ruttledge asked how far the CILs have gotten in regards to this matter. Ruttledge requested a report or some kinds of measurement on this issue for the July meeting.

Mackelprang proposed that one his graduate students, Ethan Smith, work with Alison on position paper as it relates to long-term care and de-institutionalization. The SILC already has completed paper on Long-Term Care, and this additional paper would focus on the de-institutionalization aspect of long-term care. This paper would be the formation of a “task force” revolving around the push for greater deinstitutionalization.

To this end, there was a motion made by Linda McClain that Rob Honan provide information back to the SILC at the July meeting pertaining to deinstitutionalization. Honan will provide the membership information on numbers transitioned in the first two years of the 2007-2010 SPIL, but also begin to develop the workings of a Position Paper on De-Institutionalization, which will serve as a companion to the Position Paper on Long-Term Care. Gilbert Garza seconded the motion. The motion passed unanimously with no abstentions.

A break was taken.

Speaker # 2

The next item of was a panel discussion on emergency preparedness. The panel was moderated by **Ed Kennedy** of CORD. The panelists included:

- **Craig Sicilia**, Advocate/ Educator for Brain Injury
- **John Lemus**, Self-Advocacy Coordinator for ARC of Spokane
- **Andrea Goodard**, Lilac Services for the Blind
- **Lisa Klemme-Flack**, REACH HIV/AIDS Outreach Case Manager, CORD

Ed Kennedy introduced the panelists and stressed that the panelists were going to talk in very specific terms rather than focus on any one disaster.

The First Question from Moderator Kennedy: “ What has your specific disability community done to be prepared for an emergency of any kind?”

- **Klemme-Flack**: She passed out a 100 page booklet detailing what the United Nations and the World Health Organization has accomplished with respect to preparation for persons with HIV/AIDS. Klemme-Flack will send Rob Honan the link so that he can send it to members not available to for those that need it electronically for accessibility reasons.

- Klemme-Flack also stated that health districts and first responders don't talk as much as they should with members of this population in order to become better educated
- Goodard: Lilac Services for the Blind is beginning to really start working on this issue. There have been some fire drills and things of that sort, but large scale planning has not taken place.
- Lemus: Reports that the ARC has engaged in a great deal of planning and have come up with emergency contingency plans.
- Sicilia: He reported that he works with high schools and transition programs and has provided information to parents and students, including those in supported living situations. Yet, there needs to be a great deal more of this (training) accomplished in terms of long-term plans (though short-term planning is good).

The Second Question:

“What are the mistakes made in communicating or working with people in your disability community? What are the things that do not work?”

- Klemme-Flack: Making sure of the importance of protecting consumer confidentiality: Stressing this to first responders is sometimes not accomplished. This is especially important for people who are HIV-positive.
- Goodard: The biggest mistakes are that people assume, often wrongly, the amount of sight one has based on appearances. Also, folks with blindness and vision impairments need to be more assertive in detailing their needs so that first responders and others can more effectively assist in emergency situations. Communication does not usually need to be done in a loud voice, so blind folks have to constantly educate others on how to best communicate with them.
- Lemus: One of the biggest mistakes is that people with disabilities do not effectively communicate their needs. The ARC often tells first responders that they need to communicate in a variety of ways- simply because the emergency personnel were not asking the right questions.
- Sicilia: Need to focus more on training residents or consumers of facilities instead of staff because there is high turnover of staff and consumers are usually the ones that stay on a long-term basis. So, training staff (instead of consumers) is the mistake.

3. “What do you fear the most for your (disabled) community in a disaster or emergency?”

- Klemme-Flack: Lack of food because folks with HIV/AIDS need calories and nutrition to survive, more so than the general population. Lack of medication and shelter as well.
- Goodard: The key issue would be transportation: getting to where folks need to go. Persons with blindness and low vision also need to know where their “stuff” is, such as cane, guide dog, etc.
- Lemus. “My worst fear is that first responders have little or no training when it comes to persons with DD and do not understand what is going on around them.”

In addition, lack of access to medications is a big fear as well. Further, lack of access to mobility devices is a large fear. Lastly, making sure that service animals also are adequately prepared with bones, food, blankets, water, etc.

4 “What actions might you suggest that the people in our audience might take to be better prepared to work you and your specific disability?”

- Klemme-Flack: Taking a class on the fundamentals of HIV/AIDS would be very helpful.
- Goodard: Education. Becoming more familiar with needs of Blind Community. Also, setting up meetings with agencies that work with low-vision and blind to become more fully educated.
- Lemus: Training for first responders, caregivers and medical personnel is vital. Encouraging these folks to become more aware about the needs of people with intellectual and developmental disabilities. Often first responders confuse developmental disabilities with mental illness, and this is something we need to work on.
- Sicilia: Training- the same thing everyone has stated, especially with EMTs, who think “they know it all.”

At the conclusion of the panel presentation, there was additional discussion about emergency preparedness by audience members. Among the topics of discussion were:

- Experiences gleaned from New Orleans
- Importance of stockpiling medicine
- Figuring out what to do when phone lines and other electronic forms of communication are down
- Honan suggested writing a position paper on emergency preparedness and asked the panel if they would be willing to assist
- Shelters in the Spokane area and their level of accessibility
- Dialoguing with local chapters of Red Cross
- Jim Baker brought up the fact that Clark County submits an emergency plan, and Jim encouraged those around the table to work with their counties to see that these are in fact implemented and up-to-date.
- Trina Forest mentioned some emergency preparedness activities in Pierce County and some of the workshops they are involved with.
- Chair Romel Mackelprang encouraged audience members to seek and apply for grants to increase capacity building in the area of emergency preparedness
- Lemus closed the discussion by encouraging audience members to become involved in CERT training (Community Emergency Response Team)

A short break was taken

Committee Reports

- **Department of Services of the Blind**. Debbie Cook provided the report. She stated that Older Blind Program is in the process of producing a request for qualifications for contractors to provide IL services.
 - Cook also stated that DSB is examining what should be done with their ARRA/ Stimulus funds. One thing they are looking at is infrastructure development. One potential idea is to develop an apprentice program to train individuals to be service providers for the Older Blind Program.
 - Cook discussed upgrading provider kits used in demonstrating and train for DSB customers.

- **Division of Vocational Rehabilitation**. Lynnae Ruttledge.
 - Discussed carryover funds (one year only) for Title VII Part B funds, which will turn out to be summer youth programs. Five of the six CILs will participate, and each CIL will receive about \$6,000 to administer this youth program. Each CIL will design the program to tailor it around local strengths.
 - At the previous day's Public Forum, there was a discussion on Title VII Part B ARRA/Stimulus funds for CILs. Ruttledge shared with the audience that DVR will receive \$9M in ARRA funds to be used between now and the end of 2011. She indicated that the stimulus funds will be geared towards Project HIRE.
 - Ruttledge provided information on the three DVR public hearings: May 8th in Spokane, May 11th in Tumwater and May 22nd in Seattle.

- **Rehabilitation Council for the Blind**. Diane Hansen.
 - The focus of the last meeting was spending a great deal of time discussing how consumers can participate in overall planning for budget cuts and the stimulus funding.

- **WSRC- Washington State Rehabilitation Council**. Sandra Carr
 - No Report

- **Budget Report**. Rob Honan
 - Total SILC 2009 budget: \$207,998
 - SILC has spent approximately (Honan handed out an Excel spreadsheet with exact figures) \$90,552, which amounted to 44% of year to date
 - As of current date, approximately \$18,736 (not all of the invoices have come in) was spent on the March 11th rally
 - Honan gave information on some of the higher budget year costs (interpreters, the March 11th Rally, printed information for legislators) and potential future expenses (SILC display board and additional printed materials)
 - Honan stressed that the Budget Report (rally an expense report) is very unofficial due to differences between Office of Financial Management and SILC records.

- **ACIL-WA Report.** Linda McClain.
 - McClain reports that ACIL-WA is now an official 501(c)3 agency.
 - The NCIL conference is this year in June in Washington DC and McClain believes that around 15 folks from Washington state will be attending. ACIL-WA will pay for Rob Honan to attend the conference.
 - There was a brief report on the March 11th rally, and it was very successful in terms of numbers attended. Approximately 150 CIL personnel, staff, and participants attended.
 - The Region X conference will be in Spokane in October, and McClain recommended that the October SILC meeting, originally scheduled for Vancouver, be moved to Spokane to coincide with the Region X IL conference. (Ruttledge made the comment that State Workforce Conference will also take place in October, October 28-30)

Trina Forest made a motion to move the October meeting from Friday October 9, 2009 in Vancouver to October 27, 2009 (Tuesday) in Spokane in order to support the Region X conference in Spokane. Linda McClain seconded the motion. Romel Mackelprang called for a vote. All those present approved the motion and there were no abstentions.

Lunch break was taken.

The first item after the lunch break was the **Executive Director Report.** Rob Honan

- The Report is broken into the State Plan for Independent Living priority areas of housing, transition, transportation, emergency preparedness, assistive technology, deinstitutionalization, and outreach
- There has been a large focus on outreach to Deaf Blind, but also to the Deaf and Hard of Hearing communities through quarterly meetings
- Honan reports that he has been very active in the city of Olympia's ad-hoc transportation advisory (ATAC) committee by providing recommendations on multi-modal transportation options and strategies with a disability viewpoint. Some of the recommendations included: adding additional auditory signals at stoplights, ensuring that all curb cuts are accessible, adding sidewalks if needed, verifying that all bus stops are accessible (which often includes making sure they are on a sidewalk), and adding handrails if necessary.
- Assistive Technology- Honan is continuing his work with the Washington Assistive Technology Foundation (WATF) as a board member. He is working to further connect the CIL community with AT. He worked to get Charley Lane on the WATF board, ensuring that there is more IL representation.
- Deinstitutionalization. This has not been a focus this quarter, though Honan will meet with Roads to Community Living project manager Liz Prince to discuss statewide progress of the RTCL.
- Emergency Preparedness: Attended a conference in Spokane on March 18th. Linda McClain invited him to attend and to give a brief comment about IL, the State Plan for Independent Living, and its connection to the emergency preparation. The speaker was Ana Marie Jones, a nationally renowned emergency preparation expert from Oakland, CA.

- Outreach: Honan will continue to do outreach during the Washington Youth Leadership Forum to be held at The Evergreen State College in Olympia in August.

Report on March 11th Rally: Rob Honan

- Honan provided historical information on the SILC support of ACIL-WA. In January 2007, the SILC voted to approve \$25,000 to assist the CILs and ACIL-WA in training and expanding capacity. The amount was adjusted upward to \$30,000 for FY 2009. The March 11th rally costs were derived from this source of funding
- There was a large amount of work that went into setting up this event, which was a first of its kind for the Washington SILC. Honan then deferred to SILC Executive Assistant Barbara Hathaway to explain to the Council and to audience member some details on the planning process.
- Hathaway: She discussed the joys and the barriers of setting up hotel reservations at a total of seven to begin with, but was whittled down to five at the end, dealing with interpreter assignments, ordering food from several establishments. Hathaway expressed thanks to Honan and all of the CIL staff and directors for being so supportive of her.
- The logistics of the event were discussed by Rob Honan.
 - An initial legislative training was conducted by Honan to CFI staff at the TACID office in Tacoma on March 5th.
 - Legislative Training (same as the one offered to CFI) was provided to over 100 individuals at the Phoenix Inn. Pizza was served. March 10th
 - A rally was held with several speakers in the Columbia room at the capitol building in the morning of March 11th. Toby Olson, Von Elision, and others spoke about specific issues, such as the Accessible Communities bill and the closure of Yakima Valley School.
 - Rally at the steps of the capitol at 11AM on March 11th. Rob Honan was the emcee and there were a variety of speakers from all ranges and types of disabilities.
 - Legislative visits by CILs and advocates. Folks went to visit their legislators to discuss issues of importance to them. Some examples were: (1) The Accessible Communities Bill, (2) Payday Loan/ Predator Lending regulation, (3) the closure of Yakima Valley School, (4) fighting to keep General Assistance for the Unemployable, (5) sales tax exemption on DME (durable medical equipment). Of course, the CILs all talked about the nature of their services and accomplishment to their legislators.
- Honan and Hathaway also worked after the event to see what worked and what did not for future benefit. Some of the areas of improvement brought to the attention of the SILC staff included: (1) better hotel accessibility at the Clarion Inn (especially their dining area), (2) more organized lunch process after the Rally, (3) more healthy choices for lunch and dinner. Romel Mackelprang suggested to Rob Honan and Barbara Hathaway that they provide a full evaluation of the event for the October meeting.

Other items:

- Brief Report on SILC Logo contest. The contest was extended to June 12th and to date, approximately 10 entries have been received. Honan encouraged CIL directors to continue to get the word out.
- Debbie Cook reported that the Rehabilitation Council for the Blind was suspended for two years.
- As a result of the Assisted Suicide referendum that passed last fall, there was a discussion on this issue for the state of Washington. Mackelprang reiterated that the Council is officially neutral on this issue, though he acknowledged that individuals on the Council might have different personal opinions.
- Public Comment: Linda McClain invited everyone to the CORD to visit the local CIL.

The meeting was adjourned at 2:15 pm by Romel Mackelprang